

# Independent living and disabled people in England: Are we nearly there yet and how would we know?

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# The living situations of people with learning disabilities (case example)

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- Estimate over a million people with learning disabilities in England, including:
  - Around 170,000 children age 0-17;
  - Around 930,000 adults aged 18+
  - But less than a quarter of these adults are identified as people with learning disabilities in adult health/social care services
- Projected increase in the number of adults with learning disabilities needing social care 2.0% - 2.7% per year

# The living situations of children

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- Compared to their peers, children with learning disabilities are:
  - Twice as likely to live in poor households
  - Living in families that are more likely to become poor and less likely to escape from being poor
  - More likely to experience a wide number and range of adverse life events
  - More likely to be ‘looked after’ children (children with MLD, SLD or PMLD represent 9.2% of all Looked After Children)

# The living situations of working age adults

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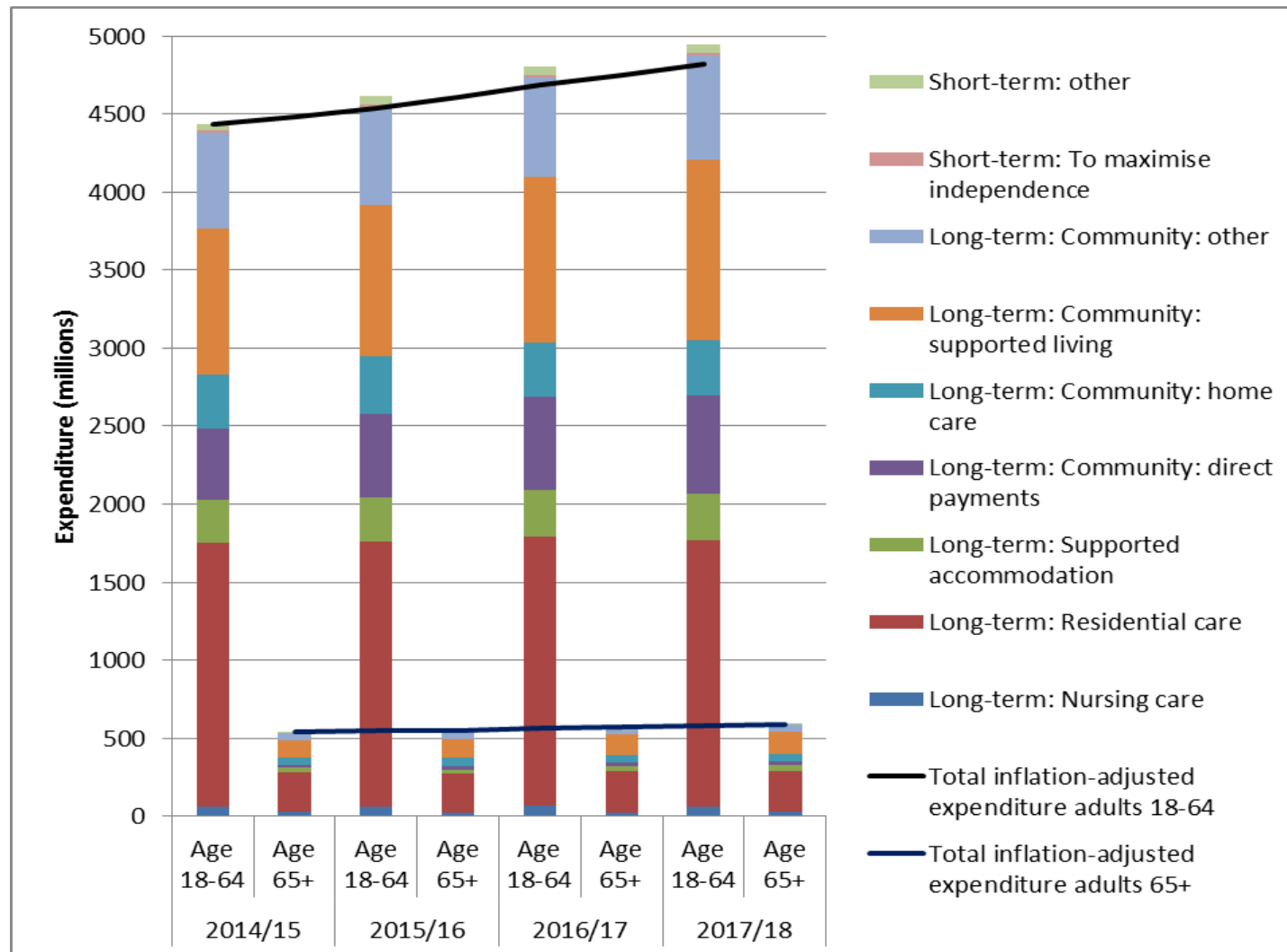
- 131,520 adults with learning disabilities aged 18-64 getting long-term social care support in 2017/18
- Most common living situations:
  - ↑ Living long-term with family/friends (37% of people)
  - ↑ Supported accommodation/group homes (22%)
  - ↓ Registered care homes (16%)
  - Tenant (LA/RSL/arms length org) (10%)

# The living situations of older adults

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- 16,395 adults with learning disabilities aged 65+ getting long-term social care support in 2017/18
  - ➔ 36% of people in residential care homes
  - ➔ 5% of people in nursing homes

# Social care expenditure



# Is any of this independent living?

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- Is what we do missing the point of Article 19?
  - Changing physical service support arrangements largely within existing institutional silos and (sometimes unhelpful) legal frameworks
  - Within a narrative of people as a ‘burden’ to be ‘cared for’ at the minimum cost to the public purse?
  - With secondary attention paid to people’s exercise of their rights and developing the infrastructure people need to fulfil the promise of independent living?

# Why is our money spent on thwarting independent living?

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- Cuts, and yet...lots of public money still being spent to stop independent living:
  - Education that doesn't encourage children to develop self-determination and an 'imagined future' for themselves
  - Residential care and inpatient services
  - New 'purpose built' residential services
  - Clustered 'supported living' with high rents and tied support
  - Benefits that stop people working
  - Personal budgets that don't give people control over what they spend (and don't trust them to spend it well)
  - Health services that can kill people



# Exploitable commodities

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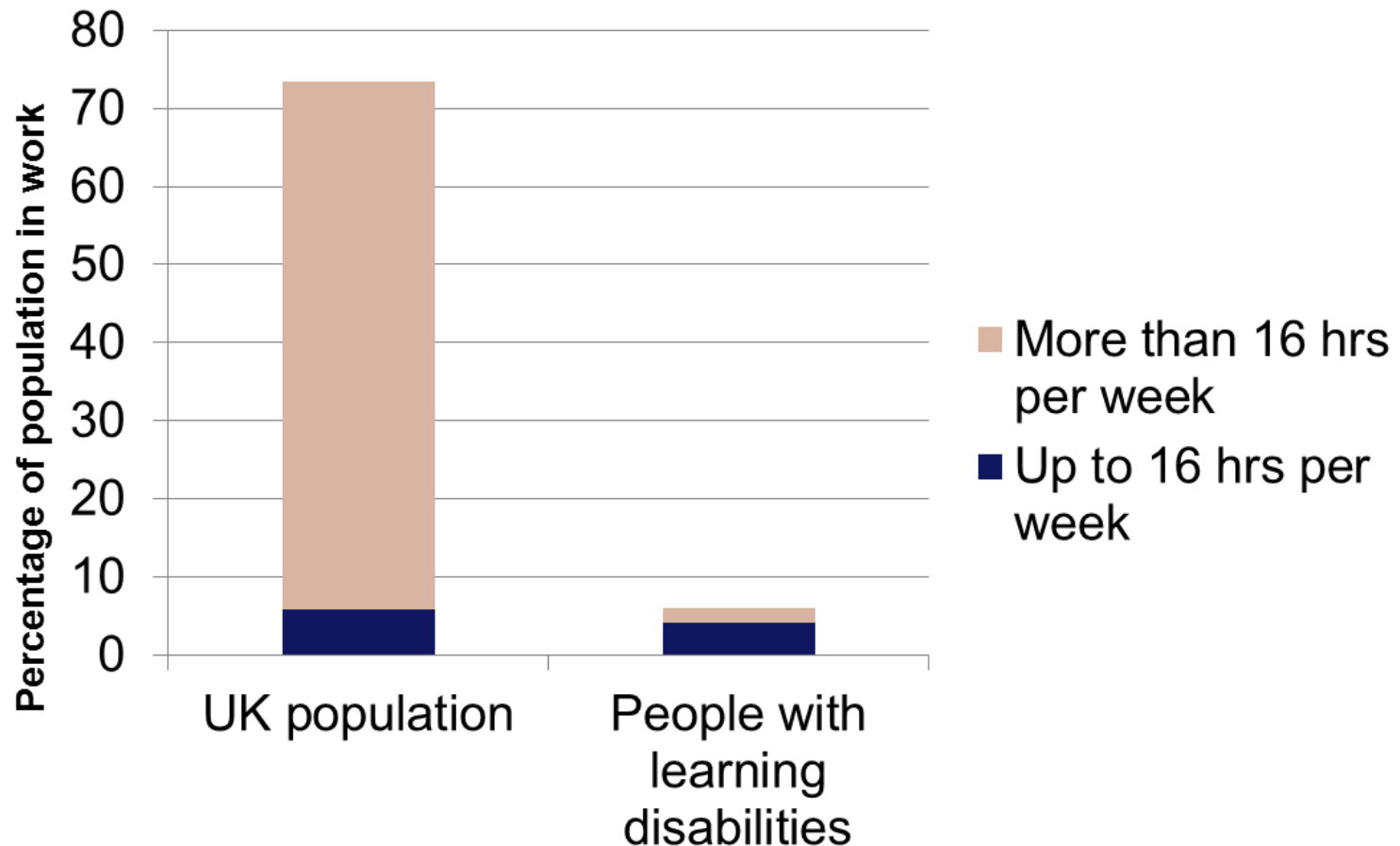
- People with learning disabilities as exploitable commodities?
  - People with learning disabilities rarely see or are in charge of most/all of the money spent
  - People with learning disabilities have to pay to work, rather than being paid to work
  - At the mercy of a ‘care market’ (private, charity and public sector)

# Independent living – how would we know if it's happening?

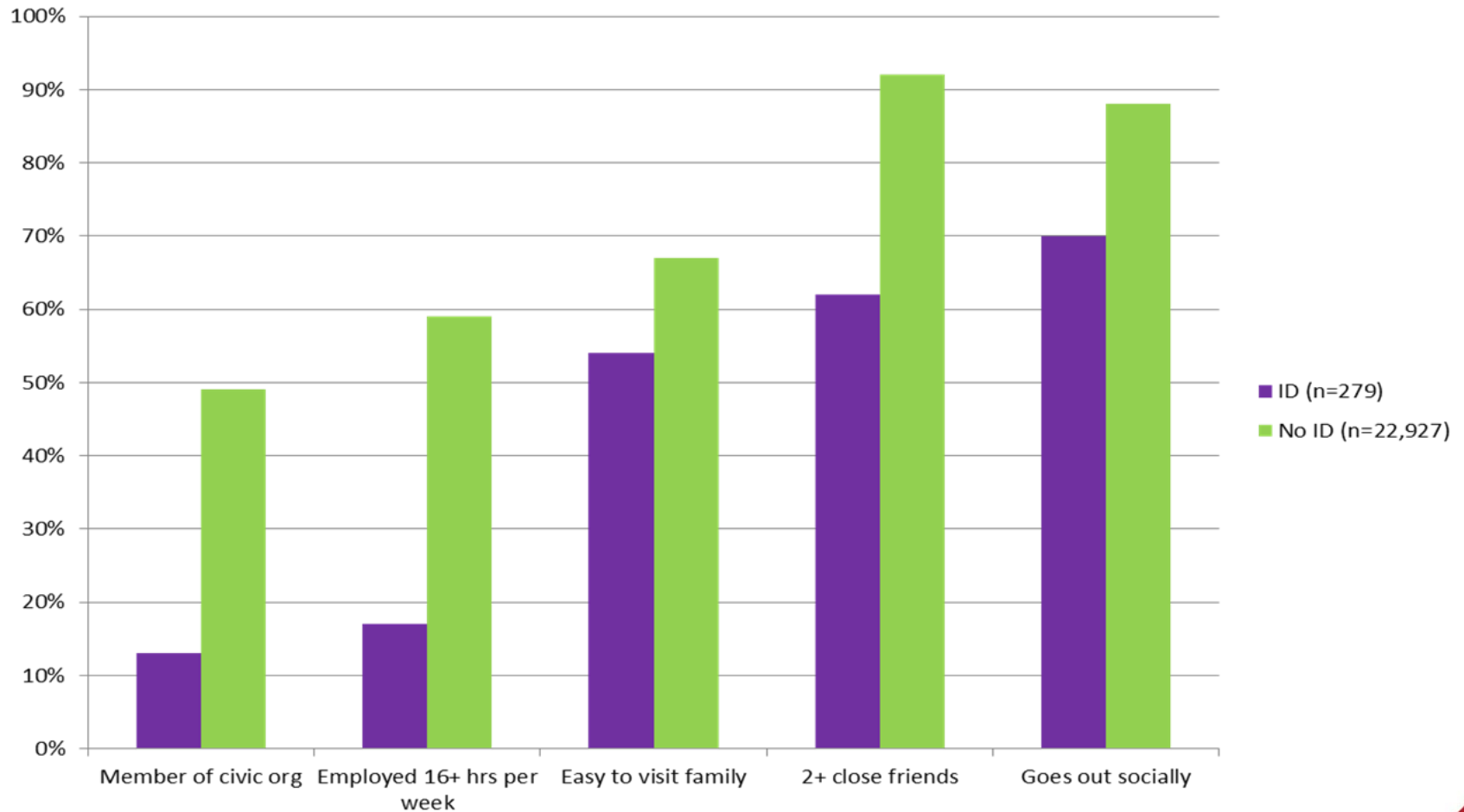
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- Is what we measure missing the point of Article 19?
  - Incoherent measurement of ‘services’ and (certain categories of) state expenditure
  - Little consideration of broader contexts of people’s lives
  - Little evaluation of whether people experience the basic tenets of Article 19, and whether people’s rights are upheld or breached
  - Little connection between what’s measured for disabled people and what’s measured for everyone else
- What would success look like, & how would we know?

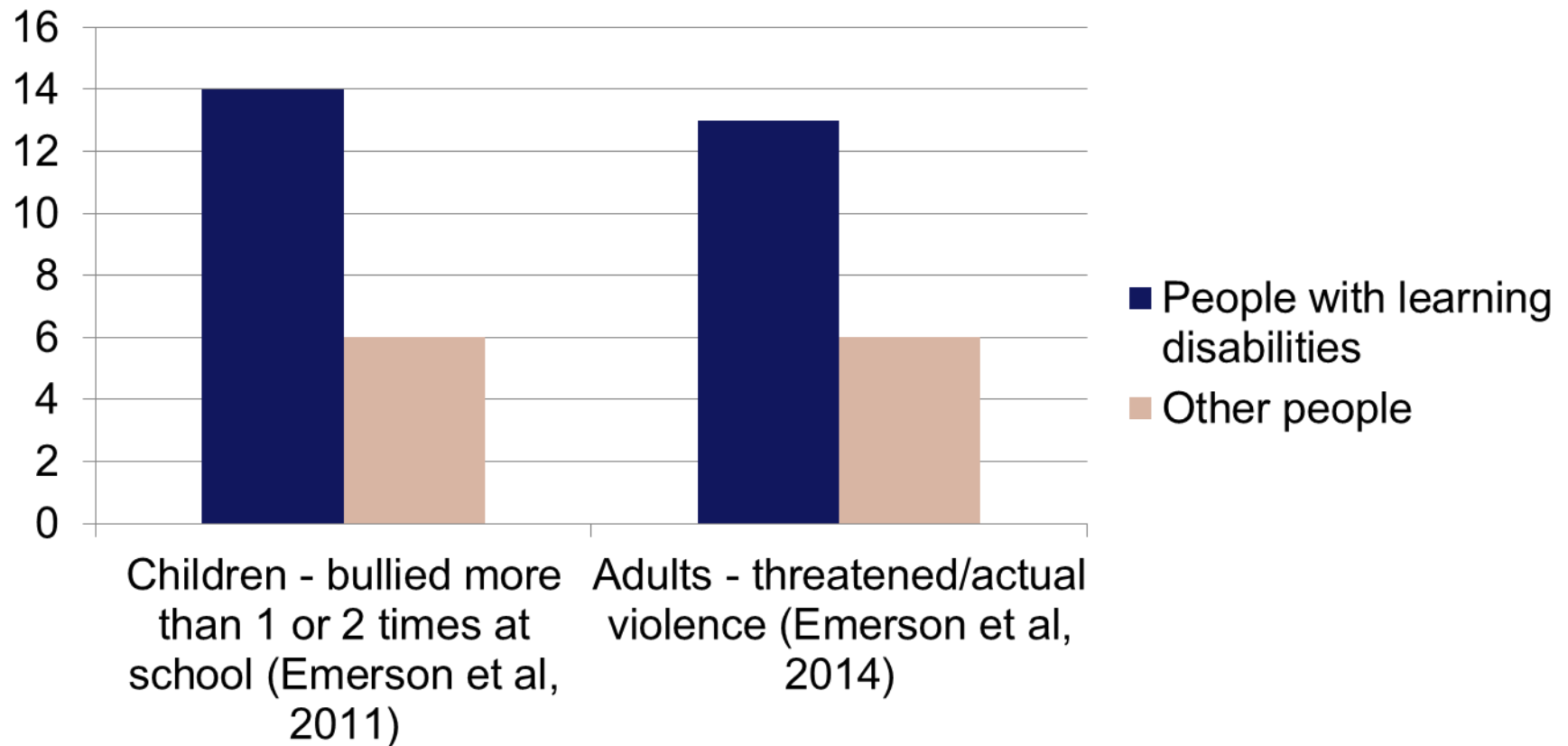
# Paid employment



# Civic & social participation



# Exposure to violence



# How have we moved from this...

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- Ministerial foreword to Valuing People Now (2009)

“This Government is determined to deliver **equality and independent living for all disabled people.**”

# To this...

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- Ministerial foreword to Valuing People Now (2009)

“This Government is determined to deliver equality and independent living for all disabled people.”
- Ministerial foreword to No Voice Unheard, No Right Ignored consultation (2015)

“Our aim is that people lead **as fulfilling and independent lives as they can**, and that they have the support **to live independently when possible.**”